Cancer Research Center Hotline

Quality of Life Research in Hawaii's Cancer Survivors

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More effective treatments and approaches to early detection have contributed to a dramatic rise in the proportions of cancer survivors over the past few decades. In 1930, only one in five cancer patients lived five or more years after diagnosis; by 1997, approximately one in two patients were survivors.[1] Over 80% of patients with Hodgkin's disease or with cancers of the breast, uterus, prostate, testis, or thyroid can expect to live at least five years after their diagnosis.

A diagnosis of cancer, as well as cancer treatment, have a significant impact on patients' daily functioning. Patients must live with physical sequelae, including short-term side effects and permanent changes due to powerful and toxic treatments. In addition, the experience of being diagnosed and treated for a potentially fatal disease may negatively affect psychological status, disrupt family and employment activities, and prompt examination of personal spiritual beliefs. "Quality of life" (QOL) is a term that is used to refer to these multifaceted outcomes experienced by a patient. While definitions of QOL vary, virtually all investigators agree that QOL in cancer patients encompasses multiple domains, or areas, of well-being including, at a minimum, physical, psychological, and social functioning.[2]

Little research has investigated how cancer-related quality of life (QOL) varies according to culture, especially in non-Western groups. Hawai'i provides a rich natural laboratory for studying this topic, due to its cultural diversity. Hawaii's residents draw upon European, Asian, and Polynesian heritages, as well as others, reflecting dramatic variations in traditional values, customs, attitudes and behaviors in almost every area of life. We are conducting research funded by the US National Institutes of Health to understand more about how ethnic and cultural variables affect QOL in cancer survivors.

One National Cancer Institute-funded study assessed quality of life (QOL) in recently diagnosed breast (N=126) and prostate (N=101) cancer patients of European American and Asian Pacific Islanders (specifically, individuals of Filipino, Japanese, and Native Hawaiian ancestry) to investigate whether QOL varied according to ethnicity. Participants were identified through consecutive registrations on the Hawai Tumor Registry (HTR), based on a diagnosis of breast or prostate cancer 4 to 6 months previously. QOL was measured by a standardized questionnaire widely-used in cancer patient populations. We found that QOL was similar across ethnic groups in most areas. However, differences were found in several domains, all in the direction of Filipino breast cancer patients reporting worse outcomes, even when clinical and demographic predictors are controlled.[3]

Another study, supported by the National Institute on Aging, investigates quality of life in long-term prostate cancer survivors and their spouses (N=181). Participants were identified through the HTR, based on prostate cancer diagnosis five (n=86), eight (n=76), or 11 (n=19) years ago. Survivors received no therapy ("watchful waiting") (n=17), surgery (n=84), or radiation (n=80). Data were collected through mailed questionnaires including standard measures. On average, the survivors were 77 years old and spouses 72 years old, and 75% were of Asian/Pacific Islander (API) descent. Overall, survivors and spouses were doing well, with mean scores of 5.6 or higher on a 7-point global QOL scale for all groups, and 14% reporting depression levels above standardized cutoffs. Survivors who received radiation therapy had significantly impaired physical and bowel function and role limitations due to decreased physical health and emotional problems, compared to surgery patients. Group differences were maintained for physical and bowel function using analyses of covariance (ANCOVA) with age as the covariate. Men who received surgery reported significantly more sexual problems than survivors who received watchful waiting or radiation. These differences persisted when patient age was included in an ANCOVA. The groups did not differ in satisfaction with urinary function. Treatment satisfaction ratings showed that wives in surgical and radiation groups were more pleased with their husbands' treatment than the survivors were. Survivors who received watchful waiting and their wives were significantly more likely to report that they would choose the same treatment again, compared to surgery-treated survivors and their wives.[4]

A National Cancer Institute-supported study compared quality of life in long-term survivors of cancers of the breast (N=239) and prostate (N=87). Cancer survivors were identified through the HTR. Eligibility criteria included: localized disease at diagnosis, no evidence of disease at most recent registry follow-up, ability to respond to written English language questionnaire, 18-30 months post-diagnosis ("short-term survivors") or 60-72 months post-diagnosis ("long-term survivors"); Filipino, Hawaiian, Japanese or Caucasian ancestry. Participants completed mailed questionnaires including standardized measures of QOL and free-response questions. Results indicated a number of differences between survivors of the two diseases: prostate survivors were more likely to report sexual problems (more than 50% in both survivors groups, compared to less than 8% of breast cancer survivors) and lower levels of emotion (both positive and negative). All groups reported making a number of lifestyle changes following their diagnosis, including stress control, spending more time with family and friends, dietary modifications, and changing priorities. Survivors of Filipino ancestry reported higher levels of stress and depression: 30% of Filipinos were rated as depressed at both time periods. Problems reported by survivors tend to persist over time (e.g., at two and five years post-diagnosis), even though most respondents across ethnic groups function well compared to population norms.[5]

Our research to date indicates that cancer survivors experience numerous changes as a result of having been diagnosed and treated for cancer. Cancer treatment related morbidities may persist even many years after treatment cessation. QOL concerns appear to differ

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in survivors of different cancer sites and ethnicities. Many survivors report positive effects of having experienced cancer, such as increased appreciation of life and changed priorities, as well as problems.

We are developing additional research to understand more about factors that predict high and low QOL. We are also exploring QOL in specified populations including survivors of more than one primary cancer, long-term cervical cancer survivors, individuals who have survived poor prognosis cancers, newly-diagnosed breast cancers, and men with breast cancer. We are initiating research projects to identify the most effective ways to provide support and assistance to cancer survivors, especially for Filipinos, who appear to be at particular risk of psychological distress. These interventions include telephone counseling delivered by lay advocates, a program to help survivors express their feelings in writing, and therapeutic massage. Our ultimate goal is to enhance well-being in cancer patients and their families by providing culturally-appropriate interventions that will assist them in achieving the highest possible QOL.

References

1. American Cancer Society. (2001). *Cancer Facts & Figures 2001.* Atlanta, GA: American Cancer Society.
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4. Gotay, CC, Holup, J, Muraoka, M. (2001, November. Quality of life in long-term prostate cancer survivors and their spouses. Abstract submitted to the International Society of Quality of Life Research Annual Meeting, Amsterdam, The Netherlands.
5. Gotay, CC, Holup, J, Muraoka, M. (1999, March). Quality of life in long-term survivors of breast and prostate cancer. Published abstract presented at the 1999 HMO Research Network Conference, Turtle Bay, Hawaii.

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